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**LOS ANGELES COUNTY**  
**COMMISSION ON HIV HEALTH SERVICES**

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3530 Wilshire Boulevard, Suite 1140 • Los Angeles, CA 90010 • TEL (213) 639-6714 • FAX (213) 637-4748

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October 12, 2004

The Honorable Board of Supervisors  
County of Los Angeles  
383 Kenneth Hahn Hall of Administration  
500 West Temple Street  
Los Angeles, CA 90012

Dear Supervisors:

**APPROVAL OF LEGISLATIVE POLICY REGARDING NAME-BASED HIV  
REPORTING IN CALIFORNIA (ALL DISTRICTS) (3 VOTES)**

**IT IS RECOMMENDED THAT YOUR BOARD:**

1. Approve a legislative policy supporting the implementation of a statewide names-based HIV surveillance system in California.
2. Instruct Los Angeles County's legislative advocates to support legislation that will help advance the replacement of the current statewide code-based HIV surveillance system with names-based HIV reporting, while preserving the option of anonymous HIV testing.
3. Instruct the Executive Officer of the Board of Supervisors to send letters transmitting this report to the Governor, the Senate President Pro Tem, the Speaker of the Assembly, the County's Legislative Delegation, and urging enactment of legislation to create names-based HIV reporting.
4. Instruct Los Angeles County's legislative advocates to pursue, in conjunction with other interested organizations, state legislation that will result in the State of California's adoption and implementation of names-based HIV surveillance in the first year of the 2005-2006 legislative session.

**PURPOSE/JUSTIFICATION OF RECOMMENDED ACTION**

Board approval of this policy will authorize the County's legislative advocates to begin working immediately with other groups in the State advocating for a transition from code-based HIV reporting to names-based HIV reporting. Names-based HIV reporting should be instituted statewide within the next year in order to avert potential federal funding losses and to end continuing County resource investment in an unreliable code-based testing system. The Commission's analysis and policy development process are described in detail in Attachment A.

Name-based reporting will significantly improve the surveillance and understanding of HIV infection in Los Angeles County. It will help to identify emerging trends in the epidemic and facilitate better priority- and allocation-setting by the Commission, and better targeting of programs and services. Conversion to name-based reporting is also vital to maximize the ongoing federal revenues for treatment and services for persons with HIV and AIDS.

### **Implementation of Strategic Plan Goals**

These actions support the County's Strategic Plan Goals of Organizational Effectiveness (ensuring service delivery systems are efficient, effective) and Fiscal Responsibility (strengthening the County's fiscal capacity).

### **FISCAL IMPACT/FINANCING**

Within three years (FY 2007), calculation of federal Ryan White CARE Act funds to Eligible Metropolitan Areas (EMAs) will convert to HIV prevalence (number of HIV and AIDS cases) from the current AIDS prevalence (just AIDS cases) formula. Unless the State's HIV reporting system supplies complete, accurate and valid data, Los Angeles County stands to lose significant revenues when this change occurs. Due to major problems with the current code-based reporting system, the only way to meet those quality standards, according to the federal Centers for Disease Control and Prevention (CDC), is through name-based reporting.

With implementation of HIV reporting—even code-based reporting—additional AIDS cases that should have been reported previously have been discovered, yielding additional revenues for Los Angeles County. Due to the challenges of a code-based system, Los Angeles County has only been able to properly match approximately 12,000 of the pending 26,000 unmatched cases, indicating that a more efficient and reliable system would be able to generate even more resources: lack of completion of HIV reporting is depriving Los Angeles County of federal CARE Act funds.

In California, code-based HIV reporting was initiated on July 1, 2002. The system requires that both laboratories, using part of the code, report positive test results, and physicians/providers complete the code and provide demographic and risk-factor information. Laboratories report each time a patient receives a test related to his/her HIV treatment (e.g., viral load testing), leading to significant duplication of HIV/AIDS case reporting. Additionally, physicians find it very difficult to comply with the requirements and often do not maintain the needed logs to compare codes with medical records (currently, only one-third are doing so).

The resulting inaccurate, incomplete and/or duplicated data consumes an extraordinary amount of County HIV Epidemiology surveillance staff time to match the lab reports with confirmed cases and to reconcile them on-site with provider medical records (when available). It is estimated that it takes twice as much time to report an HIV case by code as it does to report an AIDS case by name—leading to extraordinary expenditures of County staff and financial resources, staff burn-out, and invalid or inaccurate data.

### **FACTS AND PROVISIONS/LEGAL REQUIREMENTS**

The Commission adopted its policy in favor of names-based HIV reporting on July 8, 2004 (Attachment B) and informed the Board of its decision in a memo to the Health Deputies on September 2, 2004. Within the same motion, the Commission reiterated its continuing and ongoing support for anonymous HIV testing and the role of anonymous testing in the continuum of HIV counseling and testing (HCT) services. The Commission vote in favor of the measure was 24 -4. The Commission has since held community education forums on the subject, produced an educational videotape, and is preparing both the written materials and the education forums into Spanish for presentation to Spanish-speaking audiences in conjunction with several community-based organizations.

On August 26, 2004, the Department of Health Services sent a memo to the Board of Supervisors, again supporting name-based HIV reporting and indicating its support of this legislative policy. At the request of the HIV Commission, the Public Health Commission unanimously voted its support for names-based HIV reporting on August 12, 2004, and informed the Board of its action in a memo on August 23, 2004.

Other organizations and agencies throughout the County have adopted similar positions, including AIDS Project Los Angeles (Attachment C), AIDS Healthcare Foundation, AltaMed Health Corporation, AIDS Service Center, Being Alive Long Beach and Women Alive.

On August 3, 2004, the Governor's California Performance Review team issued a report recommending the adoption of name-based HIV reporting statewide. **Because this issue is already being considered in legislative policy discussions in California, action by the Board in advance of its regular 2005-2006 State Legislative Agenda is critical.**

### **IMPACT ON CURRENT SERVICES (OR PROJECTS)**

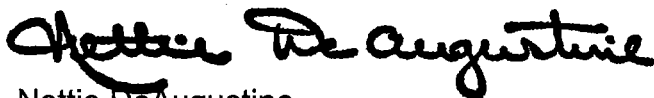
Conversion to names-based HIV reporting will take approximately two years, beginning with re-reporting previously reported code-based cases into names-based cases. In spite of time required to update current data, and report the existing backlog, the Department of

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October 12, 2004  
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Health Services will be able to facilitate the transition more easily than continued use of a code-based system.

A names-based system will reduce provider and lab burdens considerably, and will result in measurably more accurate, reliable and valid data. Costs to the County will decline over time. HIV reporting, in the meantime, will prepare Los Angeles County for the transition of federal resource allocation based on HIV instead of AIDS prevalence, and will produce data that is acceptable to the CDC. Acceptance of Los Angeles County's and the State's HIV prevalence data will make the State and the County more competitive in the search for federal and other sources of funding and resources.

Respectfully submitted,



Nettie DeAugustine  
Co-Chair



Alvaro Ballesteros  
Co-Chair

ND:AB  
CAVJ:vyg

Attachments (3)

- c: Chief Administrative Officer
- County Counsel
- Executive Officer, Board of Supervisors
- Director and Chief Medical Officer, Department of Health Services
- Director of Public Health and Health Officer
- Chair, Public Health Commission

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## **Analysis and Policy Development Process**

### ***State and Local Names-based HIV Surveillance Systems***

## **INTRODUCTION**

In concert with Los Angeles County's Department of Health Services (DHS), Public Health, its Office of Health Assessment and Epidemiology and its HIV Epidemiology Program, the Public Health Commission and numerous community groups, consumers and AIDS service organizations, the Commission on HIV Health Services approved a policy (Attachment B) at its meeting on July 8, 2004 recommending replacement of the State's current "code-based" HIV surveillance system with a "names-based" HIV reporting system. The Commission approved the recommendation with a vote of 24-4 in favor; ten of the 13 service consumer Commissioners at the meeting supported the measure. The Commission's position represents a shift in its original support, several years ago, for code-based reporting, and now corresponds with the policy that DHS adopted in 1999, reiterated in August 2004, and that the Public Health Commission approved in August 2004.

Ordinance 3.29 charges the Commission with advising the Board of Supervisors on matters related to HIV/AIDS, to act as the planning council for HIV/AIDS programs funded by the County, and to make recommendations concerning the allocation of funds expended for HIV/AIDS-related services in the County. In those capacities, the Commission concluded that continued resource investment in a code-based system that generates only partially reliable and less effective data is unwise and counterproductive.

## **HISTORY**

The State of California implemented its HIV surveillance program in July 2002, requiring counties to report cases of HIV within their jurisdictions by formula codes. Surveillance is key to the success of public health service delivery. It helps the public health system 1) understand disease impact, 2) monitor disease progression, 3) control the spread of disease, 4) secure service resources, 5) guide the allocation of resources, and 6) evaluate intervention effectiveness. More than 80 health conditions, including communicable diseases and food-borne illnesses, have been reportable for decades. AIDS has been reported by name for 23 years.

### **→ Unique Identifiers (UIs):**

The State initially legislated the implementation of a code-based system rather than names-based HIV reporting in 2000. The current code-based system relies on the use of Unique Identifiers (UIs) constructed from an algorithm of the name, birth date, gender and social security number. The resulting 16-digit UI must be reported by both the lab and provider before it can be considered an actual HIV case report; unmatched codes must be investigated.

## **CODE-BASED CHALLENGES**

Two years after the implementation of code-based reporting, it is clear that the current surveillance system is not effective in Los Angeles County nor in many other jurisdictions around the state. Since 2002, Los Angeles County's HIV Epidemiology Program (HIV Epi) has accumulated 26,000 case reports for investigation. Twelve (12) additional staff were secured for HIV Epi [paid for by carryover of federal CDC funds the first year, and through Net County Costs (NCC) since then] to help close that backlog. Even with the additional staff, HIV Epi is still 13,000 case reports behind. Approximately 40% of the investigated case reports are duplicates resulting from code errors, and the frequency rate of duplicates is expected to continue rising as the pool of HIV incidence case reports shrinks. It is projected that it will take another four years with current additional staffing to close the current backlog, not accounting for new case reports that continue accumulating during the period. The high duplicate and error rate contributes, as well, to a significant "burn out" factor among HIV Epi staff.

National, state and local data also demonstrate that code-based systems do not provide data as reliable or valid as names-based systems. While California's HIV surveillance system is as strong and comprehensive as any code-based system in the country, the code conversion is still burdened with high error and inaccuracy rates. Although no surveillance system is perfect, experience across the country demonstrates that names-based HIV reporting systems are consistently more than 95% accurate. The completeness of Maryland's code-based system, long considered the best in the country, is only 70% accurate. After both Maryland's and Texas' code-based systems were evaluated in 1997 several years ago, Texas converted to a names-based HIV reporting system.

California's dual reporting system necessitates that both providers and labs report their results. After two years, more than two-thirds of the 1,000 providers still do not keep adequate logs of the information, as required by law. Nationwide experience demonstrates that investing significantly more resources into bringing the remaining providers into compliance will result in little, if any, change in provider response. Lack of detailed data on-site further distorts and undermines the reliability and validity of HIV reporting data that must be investigated. It often renders case reports irretrievable and/or indistinguishable.

## **NAMES-BASED REPORTING OPPOSITION**

The Commission's decision to alter its original position also resulted from the recognition that the primary arguments against names-based HIV reporting are no longer valid: 1) concerns that names-based HIV reporting will deter people from accessing HIV testing and counseling services, 2) concerns that it will lead to the elimination of anonymous HIV testing and counseling, and 3) concerns about invasion of privacy and confidentiality.

→ **Potential Deterrent Impact:**

Since this debate was significantly engaged the last time in 1999-2000, the CDC-sponsored HIV Testing Surveys (HITS) have negated that names-based HIV reporting has a deterrent impact on consumer access the HIV counseling and testing services. In 23 sites across the country, over almost a decade, HITS has shown: 1) most people accessing testing services already believed their names were reported if they were aware of the surveillance system, 2) the potential that an individual's name would be reported was never a primary factor in someone's decision to get tested, and was cited as any type of factor in less than 1%-3% of the cases, 3) consumers decided not to get tested usually because they did not want to know their status or because they did not believe they were at risk, and 4) in some samples among those who were correctly aware of the type of surveillance system, results showed that they not more likely to forego testing and counseling. Other studies that might contradict the results of HITS have either been based on hypothetical behavior—which has not subsequently been supported by documented behavior—or were conducted so many years ago that their relevance today is questionable.

→ **Potential Waning Support for Anonymous Testing:**

Analysis of evidence demonstrating that names-based reporting no longer influences a vast majority of those people who decide to get HIV-tested, coupled with the Commission's strong, continued support for anonymous testing, led the Commission to its approval of names-based HIV reporting. In 1998, Nakashima published a study showing that names-based reporting did not affect testing behavior, but recommended continued support for anonymous testing. Within its motion, the Commission concurred with prevailing community and scientific opinion and continues to strongly support widespread availability of anonymous HIV testing, its pivotal role alongside confidential testing in the continuum of HIV counseling and testing services, and acknowledged that any change in the availability of anonymous testing could alter the Commission's comfort level and/or agreement with a names-based HIV surveillance system.

→ **Potential Invasion of Privacy:**

The Commission acknowledged that while stigma, prejudice and discrimination have followed HIV disease since the beginning of the epidemic, evidence does not indicate that fears of invasion of privacy or breaches of confidentiality stemming from names-based reporting are warranted. With decades of names-based disease surveillance experience and 23 years of names-based AIDS reporting, California has never experienced a confidentiality breach. There is only one documented incident of criminal HIV surveillance confidentiality breach in the country (in Florida in 1996), and, even then, no personal identifying information found its way into the public domain. Contrary to common misperception, no names or personal identifying information would be reported to the federal government in a names-based system. Names are encrypted at the state level before data is sent to the federal government. Similarly, public health surveillance data cannot be used for any other purposes (e.g., partner notification, health insurance), is statutorily protected, and is not subpoenaable.

Likewise, the relatively new Americans with Disabilities Act (ADA) and Health Insurance Portability and Accountability Act (HIPPA) have added further protections since the last time the State considered this issue. There is, however, a concern about the security of current data in a code-based system: since providers are required to keep logs of names and personal identity information, with no statutory protection guarantees, the possibility of client identity exposure is greater at the provider sites. Already, two incidents where providers have lost their logs have been noted in Los Angeles County.

## **FINANCIAL IMPACT**

Continued use of a code-based HIV surveillance system will have a negative financial impact on the County, and the State, in several ways. The Commission summarized its fiscal concerns about the program in two areas: 1) the County's capacity to continue devoting needed financing to a program that only partially meets the intended objectives, and 2) the threat that code-based reporting poses to future federal resources for HIV/ADS services.

### **→ Resource Investment:**

Reporting by codes requires twice the effort for data acquisition staff, and de-duplication of coded records takes extra data analysis staff time. The extra work requires that HIV Epi continue to maintain the 12 temporary staff for as many years as it will take to investigate and report the backlog of prevalent cases. Instead of completing this task in two years, as it would take with names reporting, HIV Epi estimates that it will take another four years at current staffing levels to catch up. This would incur an extra NCC cost of \$540,000 for an additional two years, equaling \$1.08 million for temporary contract staff.

### **→ Potential Funding Losses:**

Because 40% of the code-based case findings for HIV/AIDS are fruitless—that is, they result in no new cases reported (compared to approximately 10% fruitless investigations with names-based reporting), HIV Epi estimates that 30% fewer AIDS cases are reported each year because HIV reporting is code-based. Because Ryan White CARE Act funds rely, in large part, on AIDS case reporting, continuing coded HIV reporting may put the County at risk for further federal funding losses.

Concern about quality of data has driven the federal Centers for Disease Control and Prevention (CDC) to decline accepting HIV data from any of the jurisdictions using code-based systems, which potentially jeopardizes future federal resources for HIV/AIDS services in Los Angeles County. CDC maintains that HIV prevalence data must be more than 95% reliable, and code-based systems cannot provide those guarantees. Even if the State could demonstrate that those minimum standards are being met, it would have to evaluate its code-based programs over a two-year period: the State of California does not have the resources to implement such an evaluation.

Currently, more than 50% of the Ryan White CARE Act Title I award is based on formulae of AIDS prevalence data, and the basis for those formulae are legislatively scheduled to shift from AIDS to HIV prevalence data in 2007. There does not seem to be any movement away from that target goal in the current discussions surrounding CARE Act Reauthorization in



2005, while there are some discussions about strengthening HIV reporting mandates further. Similarly, shifts in prevention funding, housing and multiple morbidities funding may all be dictated by CDC-determined HIV prevalence in the future, which could hinder Los Angeles County's and California's access to those funding resources as well.

Presently, it is impossible to project how the change from AIDS to HIV prevalence-based formulae in 2007 will impact states continuing to use code-based systems in 2007, but there are some certainties: 1) surveillance systems are always more burdensome for larger jurisdictions, and continued use of a code-based system statewide means that smaller jurisdictions will have full data available while Los Angeles County continues to fall behind. That means that Los Angeles County, with incomplete data, will find itself at a competitive disadvantage with other jurisdictions in the state. Similarly, 2) with approximately 30% of the HIV prevalence in California, Los Angeles County's incomplete data will put the State at a competitive disadvantage with other jurisdictions across the country.

## **COMMUNITY FOLLOW-UP**

Since adoption of the policy, the Commission has done considerable work in the community to educate and inform the public about the policy and the reasons for it. The Commission's Public Policy Committee hosted two community education forums on September 14 and 15 in Van Nuys and South Los Angeles, which approximately 100 people attended. Commission members and staff have met to discuss the issue with various agencies' Boards of Directors and staffs. The Commission has also planned a series of Spanish-language educational seminars for Spanish-speaking audiences in conjunction with several organizations experienced in responding to the needs of Los Angeles County's Latino populations, and is translating its policy into Spanish. The Commission has produced a videotape of the South Los Angeles Community Education Forum that can be used by other organizations and community groups. If it can secure additional, outside funding, the Commission will have the tape dubbed into Spanish as well.

Since the Commission's original motion, County Counsel has advised that Los Angeles County is statutorily prohibited from implementing a names-based HIV reporting system independently from the rest of the state. The recommendations comprised herein recognize that implementation of names-based HIV reporting is necessary statewide, and to do so requires new State legislation. Recently, the California Performance Review also recommended statutory support of a names-based HIV reporting system.

This matter is pertinent at the present time for a number of reasons: 1) HIV Epi estimates that it will take approximately two years to convert from a code-based to a names-based HIV-reporting system. In order to be ready for the 2007 conversion to HIV surveillance, the state must convert its systems by the end of the first year of the upcoming legislative session. 2) Continued investment in the current system, beyond what is legislatively required, is no longer fiscally responsible.

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**Policy Paper Supporting**  
***State and Local Names-based HIV Surveillance Systems***

**POLICY**

The Los Angeles County Commission on HIV Health Services (Commission) supports replacing the current “coded identifier” HIV surveillance method with “names-based HIV reporting”, and the subsequent implementation of names-based HIV reporting in both Los Angeles County and statewide. The Commission adopts this policy as a public health measure, to make HIV surveillance more cost-effective and efficient in times of limited resources, and believes that concerns over the possible civil rights implications of named-based reporting of HIV—which were once the primary focus of this discussion—have declined over the years. The Commission continues to support availability of both anonymous and confidential HIV counseling and testing (HCT).

The Commission has not adopted this policy in response to the U.S. Centers for Disease Control and Prevention (CDC)’s refusal to use and report national summary statistics of HIV surveillance data collected by jurisdictions that use code-based systems. The Commission recognizes that coded identifier reporting is a viable, albeit less desirable, HIV surveillance strategy. The Commission intends to continue encouraging the CDC to include code-based HIV surveillance data in their national HIV/AIDS statistical summaries.

**RECOMMENDATION**

The Commission intends to communicate its support for names-based HIV reporting with an immediate media release, and letters to providers and funding, legislative, governmental and administrative partners. The Commission recommends and will advocate adoption of names-based HIV reporting by the Los Angeles County Board of Supervisors and the Governor of the State of California.

Both the Los Angeles County Department of Health Services (DHS) and the Los Angeles County Public Health Commission have adopted similar support for names-based HIV reporting, and it is expected that they will be critical partners in any efforts to further advance this policy.

With Board consent, the Commission will plan the introduction of this policy in the County with the Los Angeles County Department of Health Services, its HIV Epidemiology Program (HEP), Office of AIDS Programs and Policy (OAPP), Public Health Commission, and the Los Angeles County Counsel, with the aim of replacing the coded identifier system with names-based HIV reporting as quickly as possible.

## **JUSTIFICATION**

The Commission adopts this policy for three primary reasons:

- 1) to improve the public health posture of the local and statewide HIV surveillance program,
- 2) to enhance cost effectiveness of the local HIV surveillance program and ensure continued availability of HIV funding resources to the local jurisdiction,
- 3) to protect the local, statewide and national investment in sound and comprehensive HIV/AIDS prevention, care and treatment service delivery systems.

### **Improving the Public Health:**

- Names-based reporting is based on sound public health policy proven effective over time. Names-based reporting is the standard method for reporting all other reportable diseases and conditions such as tuberculosis, Sexually Transmitted Diseases (STDs), and AIDS.
- Perhaps the greatest barrier to full public acceptance of names-based HIV reporting is the perception that names-based reporting will deter people from accessing HCT services. In the early years of the epidemic, reporting systems clearly impacted whether or not people got tested. The potential for persecution or illegal use of names has changed over time as numerous legal protections have been established to protect the rights of persons living with HIV/AIDS. The Commission recognizes that as fears of civil rights violations of persons living with HIV/AIDS have subsided, concerns about funding to support early access to care and high-quality health care have increased.
- Statewide names-reporting does not dissipate concerns expressed at the last juncture of this debate, in 1999, about the potential use of the collected data. The data is still collected at numerous venues, and could be compiled through provider sites just as easily as through a central state registry. Names-based versus code-based reporting does not alter the risk of information misuse.
- If California adopted a names-based reporting system for HIV, counties would report cases to the State by name, as is done for AIDS. However, **no** patient names or other identifying information would be sent by the State to CDC or any other federal agency. Rather, HIV/AIDS cases sent to the CDC are only identified by non-named code with other personal identifying information removed.
- Actually, there is a potentially greater security and identity disclosure risk posed by multiple providers keeping logs of names and their accompanying codes—as required by a code-based reporting system—than by reporting names to a single registry—as necessary for a names-based HIV reporting system. Recently, additional protections, such as HIPAA (Health Information Portability and Accountability Act), limiting the use of health information have been implemented nationally.
- HIV Testing Surveys (HITS) and AIDS Patient Surveys (APS) across the country, including Los Angeles, have consistently shown that most people do not know what method (name or code) of HIV surveillance is used in their state, that it only minimally impacts their decisions

to get tested for HIV, and that many people assumed that after testing positive, cases of HIV are reported by name. Those findings are consistent across all populations, ethnicities and geographies (*see End-notes for citations*).

- Those same HITS studies reveal that the two primary reasons people delay or do not seek HIV testing are due to their belief that “they’re not at risk” or because they “did not want to know their status” (*see Endnotes for citations*).
- Los Angeles County and the remainder of California will continue to offer both anonymous and confidential testing, and there is no movement to eliminate anonymous testing. Only results from confidential testing are reportable, so anonymous testing still remains an option for those who truly fear having their HIV diagnosis reported by name. **The Commission strongly supports the continued availability of anonymous testing and would oppose any change.**
- In 1999, Lambda Legal Defense and Education Fund claimed that the HITS and APS findings indicated poor counseling and education at the test site rather than recognition of client knowledge about testing and reporting practices. That being said, it is still understood that absence of knowledge about reporting practices does not deter clients from presenting for HIV testing services, and once introduced to the services, anonymous testing can be offered as an alternative.
- In 1997, the CDC studied the efficacy of code-based reporting systems three years after they were implemented in Maryland and Texas. As reported in Morbidity and Mortality Weekly Report (MMMR), the study revealed that 56% of the Maryland providers were not keeping cross-reference logs, and the codes were incomplete 39% of the time. The findings from the evaluation of code-based reporting in Texas were also unfavorable, and Texas abandoned its code-based system in favor of names-based HIV reporting shortly after the evaluation was completed (*see Endnotes for citations*).
- The validity, reliability and utility of code-based systems are severely compromised when the codes are incomplete, incorrect, and/or when the code reported for individuals living with HIV/AIDS is constructed differently over multiple reports. Incomplete and/or incorrect codes are a common occurrence, and deconstructing a code to reconcile provider and lab records is difficult, extremely time-consuming, and, at times, unsuccessful. Public health effectiveness is based on reliability of data and accompanying information.

**Enhancing Cost Effectiveness:**

- The coded identifier reporting system is inefficient and expensive. One case requires both a lab report and a provider report. HEP must send employees to provider sites to reconcile the records when one or both parties have reported incomplete or inaccurate codes. Since most providers are not maintaining a cross-reference log, it is difficult, and at times impossible, to link the lab notification with the appropriate medical record.

- The error and incomplete record rate of code-based systems is significantly higher than those of names-based systems. When the higher cost of the coded identifier surveillance system is added to the equation, it equals a tremendously cost-ineffective solution.
- It is no surprise that the accuracy rate of a code-based system is diminished compared to a names-based system. The opportunities for mistakes are exponentially greater: multiple parties must enter the information, convert it properly, and submit it properly; the client must reveal the same personal identifying information; and the multiple parties must chart and record the information consistently.
- HEP estimates that it takes twice as long to report an HIV case through the coded identifier system as it does through a names-based system.
- Health care providers have a long-standing history of poor adherence to disease reporting laws/regulations. Compliance with maintaining a cross-reference log has been poor in all jurisdictions that require cross-reference logs as part of their code-based HIV surveillance laws/regulations. HEP estimates that only one-third of providers are maintaining a log in Los Angeles County, as is required by the HIV reporting regulations.
- Currently, HEP reports that approximately 15,000 out of an estimated 26,000 non-AIDS HIV cases seeking care in Los Angeles County have not been reported, despite the addition in Spring of 2003 of 12 temporary staff assigned to HIV/AIDS surveillance activities. These temporary positions are not funded beyond September 2004, and no potential sources of replacement funds to support them have been identified.
- The Commission does not believe that Los Angeles County has the capacity to maintain an adequate code-based surveillance system, especially when other, less expensive options are available. The time-consuming nature of the work, the sheer size of LA County, and the introduction of rapid testing all exacerbate the equation further. Additional resources in a shrinking funding environment must be devoted to the current surveillance system in order to catch up with the significant backlog of reported cases, and then to maintain it at appropriate levels. Additional dollars to finance those additional activities might have to come from service funds.
- To date, the monthly number of potential cases identified for investigation exceeds the number of HIV case reports completed monthly, making it difficult to predict when the reporting system will have a reasonably complete count of HIV cases.

**Protecting the Investment of HIV Resources:**

- Failure to report accurate HIV prevalence rates will lead to reduced Federal and State HIV/AIDS funding awards to the County, especially related to Ryan White CARE Act Title I/II and HOPWA funds, and within the formulas used to allocate Titles III/IV and Part F awards.

- The State's epidemiologist reports that converting from a code-based to a names-based reporting system could be relatively efficient and speedy.
- Funding reductions will occur on two fronts: 1) incomplete data sets will not be or will only partially be accepted by the funding sources, and 2) Los Angeles County will lose in competition for those dollars with other jurisdictions either because the other jurisdictions are using names-based HIV reporting and/or because they are more compact/more dense and can collect the data more easily.
- Conversion from a coded identifier to a names-based HIV reporting system must occur immediately in order to be fully operational and producing accurate and adequate data by the 2007 benchmark dates in the Ryan White CARE Act legislation.
- As previously noted, the coded identifier system penalizes Los Angeles County and puts it at a distinct disadvantage, even in comparison to other jurisdictions in the state. The diversity, geography, and sheer size of Los Angeles County adds to the time-consuming nature of the work, and effectively renders Los Angeles County less competitive in comparison to other state and national jurisdictions.
- Names-based HIV reporting is the prevailing attitude among public health communities and among funding sources. Continuing to advocate for a decreasingly popular and accepted surveillance approach—especially one as intrinsically flawed and challenging as coded identifiers—does not advance or maintain Los Angeles County's and California's position at the forefront of response to the epidemic.
- Code-based systems do not lend themselves easily to uniformity or client follow-up across the country. For example, it is virtually impossible to track a client's migration to different states if multiple codes and formulae are used to identify him/her.
- Health planners must ask themselves if the confusion engendered by lack of surveillance uniformity best serves the needs of clients and/or their care systems. Twenty-three years into the epidemic, names-based HIV reporting gives the local jurisdiction maximum opportunity to both maintain and enhance its investment in the local health care and social service system, and to find a proactive, not reactive, response to the epidemic.

### **POLICY ADOPTION**

The Commission's Joint Public Policy (JPP) Committee adopted this policy favoring names-based HIV reporting on Friday, June 18, 2004 by a 5-1 vote, and delegated authority to develop this policy paper to a volunteer workgroup. The policy paper was then presented to the Commission's Executive Committee on Monday, June 28, 2004, and the Committee voted unanimously (8-0) to approve it and forward it to the Commission. The full Commission considered it at its meeting on July 8, 2004, and adopted it with a 24-4 vote in favor. Those supporting the policy include almost all of the Commission's consumer members.

**ENDNOTES**

Centers for Disease Control and Prevention (CDC), “Evaluation of HIV Case Surveillance Through the Use of Non-Name Unique Identifiers—Maryland and Texas, 1994-1996.” Morbidity and Mortality Weekly Report (MMWR), 1998, Vol. 46, pgs. 1254-1271.

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September 10, 2004

Los Angeles County Commission on HIV Health Services  
3530 Wilshire Blvd., Suite 1140  
Los Angeles, CA 90010

Dear Commission Members:

AIDS Project Los Angeles (APLA) supports the decision of the Los Angeles County Commission on HIV Health Services to recommend replacement of the state's current coded identifier HIV surveillance system with a names-based HIV reporting method.

We understand that the Commission's decision was the result of a lengthy public discussion, and appreciate its efforts to involve the community in the process. APLA believes that names-based reporting is in the best interest of Los Angeles County for several reasons.

We believe that the limitations imposed by a code-based HIV surveillance system adversely affect the ways in which Los Angeles and California can address the HIV/AIDS epidemic. Planning a strategic and comprehensive response to the HIV epidemic requires reliable data. For many reasons, the current coded identifier HIV surveillance system has not been able to produce consistent, dependable data. Code-based reporting continues to be a more complicated and less efficient mechanism than a names-based system. After two years, County surveillance activities have only been able to gather approximately half of the estimated current HIV cases. The development of a names-based system would result in more reliable and complete data on HIV infection, and would facilitate improved planning of Los Angeles County HIV prevention and care efforts.

A names-based HIV reporting method will enhance California's prospects for continued and potentially increased funding resources. The Ryan White CARE Act Reauthorization of 2000 directed the U.S. Department of Health and Human Services to examine whether HIV reporting and surveillance could be used to restructure its funding formulas by 2007. Currently, the Centers for Disease Control and Prevention (CDC) does not accept HIV data using code-based reporting systems from 15 jurisdictions, due to these systems' inability to meet the CDC's standards of quality and reliability. This non-acceptance of code-based HIV data will seriously impede CARE Act funding to Los Angeles County and the state of California unless a more efficient means of collecting HIV case data, such as names-based reporting, is implemented immediately.



APLA understands the concerns of some community members who oppose names-based reporting on the grounds that it is likely to deter people from getting tested. We believe that the continued availability of anonymous HIV testing adequately addresses this concern. Furthermore, HIV Testing Surveys (HITS), anonymous cross-sectional surveys conducted in 23 states, have demonstrated that fear of being reported by name to the government does not impact testing rates. In fact, one 2002 HITS report by the Los Angeles County Department of Health Services indicated that individuals who believed California had names-based reporting were more likely to get tested.

Some community members have also raised the possibility of confidentiality breaches using a names-based reporting system. As noted by the Commission, the last significant breach of HIV names confidentiality in the U.S. occurred in September 1996 in Florida, prior to that state's implementation of HIV reporting. Even in this incident, no names were released to the public. Neither Los Angeles County nor California has experienced any confidentiality breaches in more than two decades of experience with HIV/AIDS.

Because the deadline imposed by CARE Act legislation is 2007, the Los Angeles County has only a limited period of time in which to implement an efficient system of collecting complete HIV case data. We as a community must take the necessary step toward developing a viable public health policy that ensures the health and well-being of Angelenos living with HIV/AIDS. Names-based HIV reporting represents our best option for protecting resources and saving lives.

Sincerely,

A handwritten signature in black ink that reads "Craig E. Thompson". The signature is written in a cursive, flowing style.

Craig E. Thompson  
Executive Director